2024

Annual Report

This report celebrates the strength and resilience of the Spina Bifida community while highlighting the transformative impact of your support in 2024.

Explore More
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SPINA BIFIDA
ASSOCIATION

From the CEO’s Desk

Dear Spina Bifida Family,

As I reflect on 2024, I am filled with gratitude and pride for all that the Spina Bifida Association (SBA) has accomplished—achievements made possible because of you. Thanks to your generosity, we’ve reached new milestones in education, research, advocacy, and community building, each bringing us closer to a brighter future for individuals and families living with Spina Bifida.

This year, our **Virtual Education Series** tackled topics critical to daily life, providing resources and empowering individuals with knowledge to thrive. Our groundbreaking research initiatives addressed challenges such as bowel and urinary continence, mental health, self-management, and weight management, while also advancing transition care and clinical studies. These efforts continue to shape the quality of care and improve outcomes for our community.

In advocacy, we raised our collective voice through **Teal on the Hill** and mobilized grassroots action with tools like Voter Voice to ensure the needs of our community are heard at every level. Our emphasis on community building fostered connection and support, from expanding our Expectant Parent Network to strengthening resources through our **National Resource Center** and **NPPACT**.

The progress we’ve made this year stands as a testament to the resilience and determination of the Spina Bifida community—and the unwavering support of donors like you. Together, we are creating a world where individuals with Spina Bifida can lead full, empowered lives.

As we look ahead to 2025, I invite you to continue this journey with us. Together, we are not just meeting challenges; we are building solutions, one step at a time.

With heartfelt gratitude.

Sara Struwe

President & CEO

Mission, Vision, & Values

Our mission is to build a better and brighter future for all those impacted by Spina Bifida.

Research:

We advocate for research to improve the lives of people living with Spina Bifida, driving initiatives like the National Spina Bifida Patient Registry (NSBPR) and the Urologic Protocol for Young Children with Spina Bifida, both housed at the CDC, while collaborating with hundreds of healthcare professionals worldwide to update the Guidelines for the Care of People Living with Spina Bifida, identifying research gaps that will shape our agenda, prioritize community-driven needs, and encourage the use of NSBPR data to secure funding and advance care.

Education & Support:

Through the National Resource Center, the Spina Bifida Association provides one-on-one information and guidance for families, individuals, providers, and others whose lives have a connection Spina Bifida. SBA offers in-person and virtual programs featuring medical experts, parents, and adults with Spina Bifida covering topics identified by the Spina Bifida community.

Advocacy:

We are dedicated to ensuring the voice of people with Spina Bifida is heard on Capitol Hill. Together, we can make a difference in the lives of those with Spina Bifida. We will not rest until every person has access to coordinated, affordable, comprehensive care.

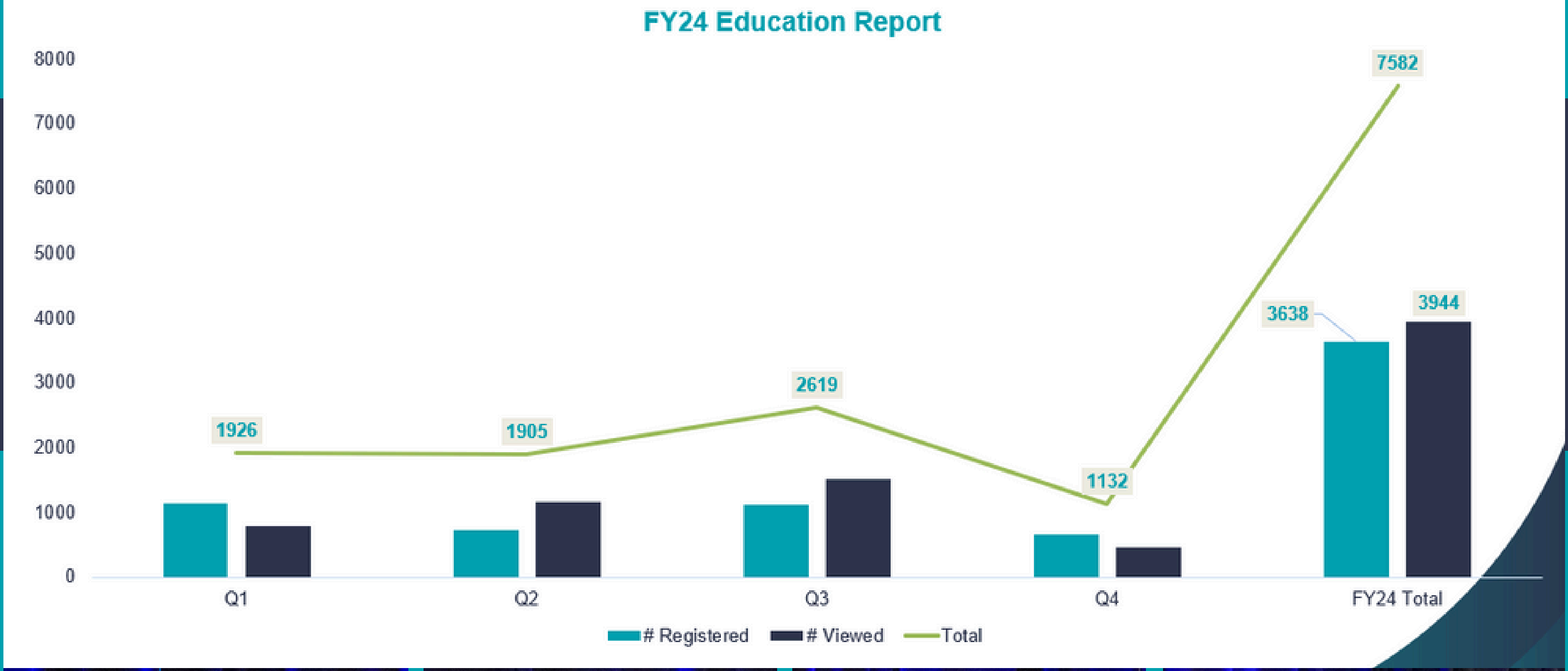
Community Building:

Whether you have Spina Bifida; recently learned that you are expecting a child with Spina Bifida; are a parent, family member, caregiver or other loved one of a person with Spina Bifida; or provide health care or community services to people with Spina Bifida, SBA's staff and network of healthcare providers, Chapters, local advocates, and families and adults with Spina Bifida are here to link to you the connections you need.

2024 Achievements

Education

In 2024, the Spina Bifida Association's Virtual Education Series continued to empower individuals and families by addressing critical topics that directly impact their lives. Through interactive webinars and expert-led discussions, we tackled essential issues such as bowel management, transition care, weight management, and mental health. These sessions provided practical tools, expert insights, and a supportive environment for learning and growth. With hundreds of participants nationwide, this series ensured that knowledge was accessible and tailored to the unique needs of the Spina Bifida community. Each session reinforced our commitment to education as a cornerstone for improving quality of life and fostering independence.



Research

In 2024, the Spina Bifida Association made significant strides in advancing research that addresses the most pressing needs of our community. Through targeted initiatives and collaborative partnerships, we focused on improving quality of life and care in areas such as mental health, bowel and urinary continence, self-management, weight management, and transition care. Our advisory council and clinical partners played a pivotal role in driving these efforts, ensuring our research agenda remains community-centered and impactful. Highlights included groundbreaking studies on continence management, the integration of PROMIS anxiety and depression measures in clinical care, and the development of tools for effective self-management. These advancements underscore our commitment to empowering individuals with Spina Bifida through evidence-based solutions.

Support for Studies

Bowel Continence

SB Genetics

Weight Management

Disability & Vocation

MOMS Study

Urinary Continence

Reproductive Health

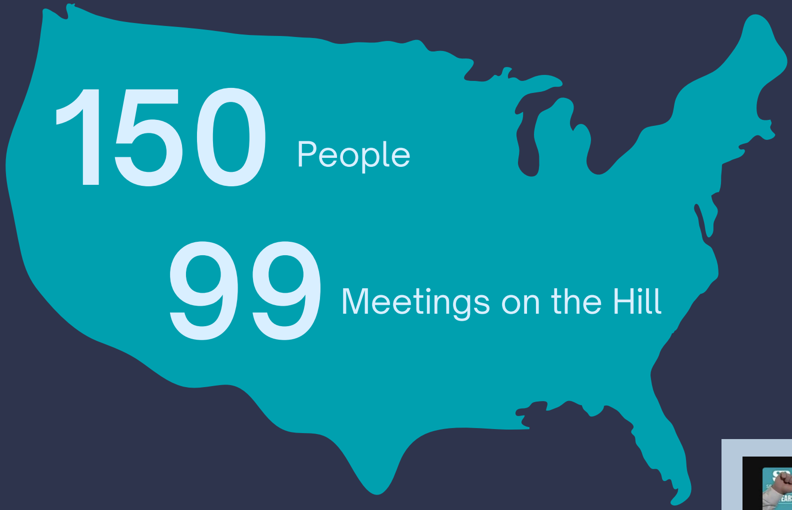
Prenatal Possibilities

Mobile Apps

TEAL
ON THE
HILL
2024
SPINA BIFIDA
ASSOCIATION

Advocacy

In 2024, the Spina Bifida Association amplified the voices of our community through impactful advocacy efforts. Our signature Teal on the Hill initiative brought together passionate advocates who shared their stories with policymakers, ensuring that the needs of individuals with Spina Bifida were heard at the highest levels. Through tools like Voter Voice, we mobilized grassroots support, generating thousands of messages to lawmakers and advancing critical policies that support health care access, disability rights, and research funding. These efforts strengthened our presence in legislative conversations, empowering our community to drive meaningful change. Advocacy in 2024 was not just about raising awareness but about building a stronger future through collective action.



150 People

99 Meetings on the Hill

Community Building

In 2024, the Spina Bifida Association strengthened connections across our community through impactful initiatives that provided support, resources, and shared experiences. Programs like the Expectant Parent Network offered essential guidance and hope to families preparing for life with Spina Bifida, while the National Resource Center served as a trusted hub for reliable information. Social media platforms fostered engagement, creating spaces for individuals to connect, share stories, and celebrate achievements. Meanwhile, the NPPACT program empowered parents and caregivers to become leaders in advocating for their children and building local networks of support. These efforts reflect our commitment to fostering a vibrant, inclusive community where everyone feels seen, supported, and valued.

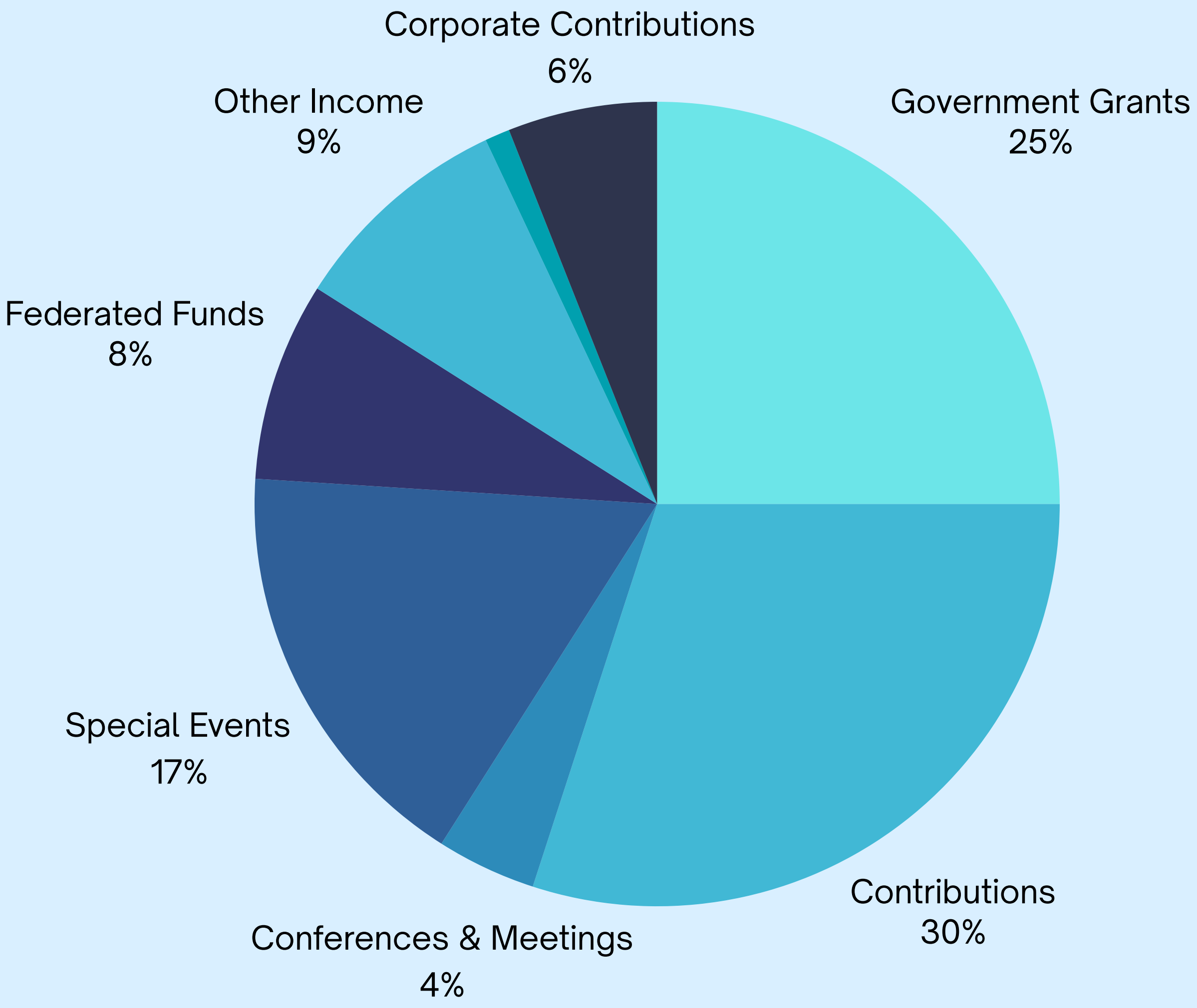
Outreach & Support

	Instagram	Facebook	Total Touches
Social Media	128,460	159,311	287,771

	Cases	Cases Per Month	Hours of Interactions Per Month
National Resource Center	218	18	25

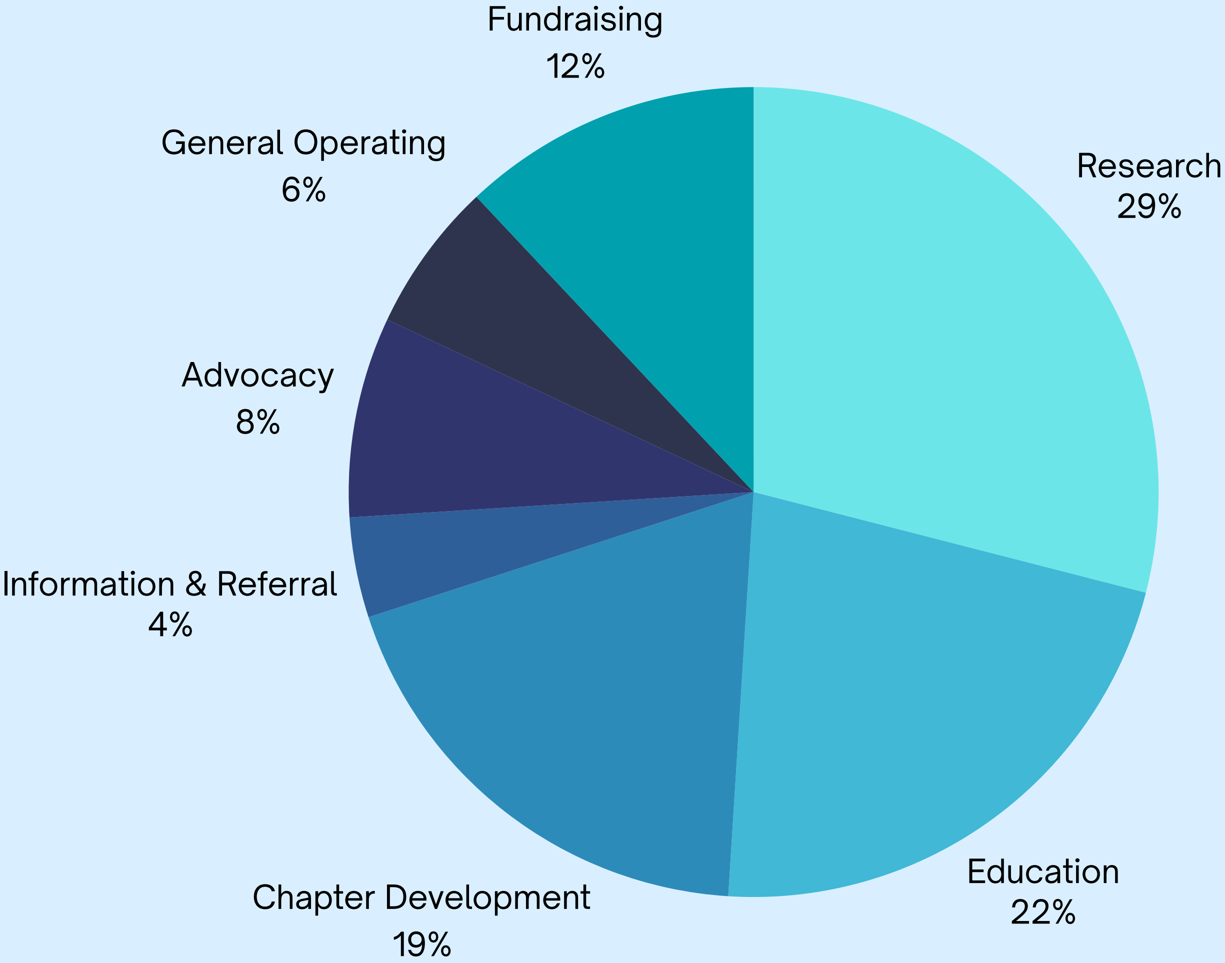
Financial Summary

Total Revenue and Support



**Please note these numbers have not yet undergone an audit.*

Expenses



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Net Assets

Net assets represent the Spina Bifida Association’s financial position and its ability to sustain and advance its mission. These assets ensure the long-term stability of SBA, allowing us to serve the Spina Bifida community effectively while maintaining financial transparency and accountability.

Net Assets at the Beginning of the Year: $704,040

Net Assets at the End of the Year: $971,489

↑ 38%

Our Partners

180 Medical
AbbVie
Aeroflow Urology
Alliance Prosthetics & Orthotics
American Academy of Pediatrics
BD
Biotechnology Innovation Organization
Byram Healthcare
Carolina Neurosurgery & Spine
Children's Healthcare of Atlanta
Children’s Hospital of Philadelphia
Coloplast
Comfort Medical
ConvaTec
Driver Rehabilitation Services
Duke Children's Hospital
Ernst & Young LLP
Georgia State University
Hartmann
Heartfelt Comfort Care
Hollister Inc
Holy City Pediatric Therapy
Johns Hopkins All Children's Hospital Institute for Brain Protection Sciences
Los Angeles Fetal Surgery
Maxwell Medical Services
Novartis Pharmaceuticals
ABLE United
Nemours
Neurofit360Atl
New Heights Pediatric Therapy
Oaktree Capital Management
Omni Healthcare Services
Orlando Health
Palmetto Home Medical
Piedmont Medical Solutions
Quality Care & Love
Rhaeos
SE ADA Center
Shield Healthcare
SHOWAbility
Shriners Children’s
Smith+Nephew
Strive Medical
Sunrise Medical
UC Davis Fetal Care & Treatment Center
UT Health
Vanderbilt University Medical Center
Wellspect
Wright Close & Barger

Volunteer Recognition

2024 Walk-N-Roll Ambassadors

Colt & Jordan Kirby
Charleston Walk-N-Roll

Alicia Alibrando
Sacramento City Walk-N-Roll

Audra Beasley
Oklahoma City Walk-N-Roll

Rose Calvert
Nashville Walk-N-Roll

Mary Wilson Joseph
Atlanta Walk-N-Roll

Marie and Danielle Delgado
Greensboro Walk-N-Roll

Eric Tobin
Los Angeles Walk-N-Roll

Marissa & Lenny Miles
Orlando Walk-N-Roll

Maranda & Carson Jones
Houston Walk-N-Roll

Anya Kewley
Walk-N-Roll Your Way (CA)

Leigh Herndon
Walk-N-Roll Your Way (GA)

2024 Board of Directors

Nancy Gore, Chair
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Immediate Past Chair
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Sheliah ROy
Kathyrn Smith, RN, MN, DrPH
Bryan Vodicka
Dawne Widener-Burrows
Melissa Wiegel
John Wiener, MD

Stories of Impact

Hope Starts Here: Empower Families from the Diagnosis

When Jessica received her son Parker's Spina Bifida diagnosis, she was overwhelmed by fear and uncertainty. Doctors painted a bleak picture of what her family's future might look like, leaving her feeling isolated and lost. That changed when she connected with another mother through the Spina Bifida Association's Expectant Parent Network. This connection gave her more than information—it gave her hope. Years later, Jessica became a mentor herself, offering guidance, encouragement, and the same spark of hope to new parents facing similar challenges.

One of those parents was Megan, who had just received her son Wyatt's diagnosis. Like Jessica, Megan felt overwhelmed by worst-case scenarios and uncertainty. Jessica's outreach, complete with photos of Parker thriving and happy, became a lifeline. Through the Expectant Parent Network, Jessica and Megan formed a bond that grew beyond mentor and mentee—they became close friends, sharing milestones like playdates and birthday parties. Their story is a testament to the power of connection, resilience, and the supportive community fostered by the Expectant Parent Network.

READ MORE

Stories of Impact

Building Community, One Family at a Time

For the Kennedy family—Jasmin, Skylar, and their daughters, Reagan and Emily—attending their first Walk-N-Roll was more than a day in the park; it was a transformative moment of connection and celebration. Reagan, a spirited three-year-old with Spina Bifida, was greeted with joy, warmth, and acceptance. At Walk-N-Roll, her name wasn't whispered with pity but shouted with pride, as the family discovered a vibrant community that embraced and uplifted them.

The event provided the Kennedys with more than just a network of resources and practical advice—it gave them a sense of belonging. Meeting families they had only known online brought a newfound comfort and solidarity, showing them they weren't alone in their journey. For Reagan, it was an opportunity to see others who shared her experiences, and for her parents, it was the realization that support and understanding were only a call or meeting away. As the Kennedys left Walk-N-Roll, they carried with them not only cherished memories but also the promise of a brighter future built on shared strength and connection.

READ MORE

Get Involved

Advisory Councils

We are actively recruiting for Advisory Council members for the following SBA Chapters listed below. The Advisory Council organizes the annual Walk-N-Roll fundraising event, along with various social and programmatic activities that support and serve members of the Spina Bifida community in their geographic area.

SBA Chapter of California
SBA Chapter of Carolinas (NC/SC)
SBA Chapter of Florida
SBA Chapter of Georgia/Tennessee
SBA Chapter of South Texas

If interested: Complete the volunteer form

Walk-N-Roll

Interested in getting your local community involved with the 2025 Walk-N-Roll Season this year? Consider planning a Walk-N-Roll Your Way event. Learn more on the Walk-N-Roll website or reach out to us at walknroll@sbaa.org for more information.

Give

Your support makes a difference! Join us in empowering the Spina Bifida community by making a donation today. Together, we can continue providing life-changing education, advocacy, and support to those who need it most.

Thank You

You are the heart of our mission and the driving force behind the progress we've made. As we look to the future, we are inspired by your unwavering support and the impact we can continue to achieve together.

From all of us at SBA, thank you for being a part of this journey. Together, we are Spina Bifida Strong.

☎ (800) 621-3141

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